Health Canada Santé Canada

CANADIAN STRATEGY
on Palliative and End-of-Life Care

PROGRESS REPORT
OF THE COORDINATING COMMITTEE

December 2002 to March 2004

Canada

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ACKNOWLEDGEMENT

The Coordinating Committee of the Canadian Strategy on Palliative and End-of-Life Care' community component would like to commend the work of Senator Sharon Carstairs. During her appointment as Minister with Special Responsibility for Palliative Care (March 2001 to December 2003), Senator Carstairs raised the profile of palliative care with her federal colleagues. She worked tirelessly on numerous outreach activities across the country; meeting with her provincial and territorial counterparts, hospice and palliative care organizations, hospital administrators, caregivers, dying individuals and their families, and speaking at every opportunity about this precious part of life. As champion and advocate for the best quality of care for all Canadians who are dying, her efforts supported the palliative care community in its work to advance the issues.

The Committee would also like to extend its appreciation to the staff of the Secretariat on Palliative and End-of-Life Care for their continued support to enable advancement of the community component of the Canadian Strategy on Palliative and End-of-Life Care, and to Health Canada for its funding support of palliative and end-of-life care projects and initiatives. We look forward to the continued work of this invaluable relationship to improve the provision of quality palliative and end-of-life care for Canadians.

PREFACE

In 2001, the Government of Canada formally demonstrated its support toward advancing palliative and end-of-life care for Canadians by first appointing Senator Sharon Carstairs as Minister with Special Responsibility for Palliative Care (March 2001) and secondly, by establishing the Secretariat on Palliative and End-of-Life Care at Health Canada in June of that year. The Secretariat was directed to facilitate collaboration and coordination of effort with other federal government departments and agencies, representatives of national associations, professional associations, universities, researchers, the community, and, provincial and territorial governments.

In 2002, the Government of Canada furthered its commitment to palliative and end-oflife care through a proposed plan for the development of a collaborative, national strategy to improve palliative and end-of-life care for Canadians. The proposed plan was presented to the Cabinet Committee on Social Union (CCSU) by the Minister of Health, Anne E. McLellan and the Minister with Special Responsibility for Palliative Care, Senator Sharon Carstairs. As part of this initiative, it was agreed to report on the progress of activities up to the end of March 2004.

It is not the intent nor the capacity of this report to present all of the successes and activities external to the efforts of the Coordinating Committee and those involved in the development and implementation of the Canadian Strategy on Palliative and End-of Life Care. The following report provides: (1) a brief overview of events leading to the establishment of the Coordinating Committee and five working groups of the Canadian Strategy that are developing and implementing the community component of the Strategy; (2) an overview of their initiatives and accomplishments thus far; (3) the challenges in developing and implementing a national strategy on palliative and end-oflife care; and, (4) suggested future directions for this collaborative initiative.

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Members of Coordinating Committee and Working Groups ..... **Appendix I**

For more information about the Coordinating Committee, the Working Groups and the Canadian Strategy on Palliative and End-of-Life Care please contact:

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BACKGROUND

It is society's responsibility through government, health care planners, professional organizations, and health professions to provide the resources to ensure a system of intensive caring for dying patients and their families. This necessitates the development of the field of palliative care to ensure that the appropriate expertise is widely and readily available as well as accessible to all.

(Presentation to Special Senate Committee on Euthanasia and Assisted Suicide, MacGregor 4:53)

In June 1995, the Special Senate Committee on Euthanasia and Assisted Suicide released its report, Of Life and Death, after hearing testimonials from Canadians across the country over a 15 month period. In addressing the issues around euthanasia and assisted suicide, it became clear that one of the most pressing reasons for a person to consider such action was the fear of a painful, lonely and degrading death. A number of recommendations were made that could result in improved access to palliative and end-of-life care services, standards of care at end-of-life, and an increase in the knowledge and training of professionals.

A follow-up investigation into the progress of these recommendations by the Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology led to the June 2000 release of Quality End-of-Life Care: The Right of Every Canadian. The Senate Committee discovered that little action had resulted from the previous recommendations at the federal level. It strongly recommended federal leadership and the collaborative development of a national strategy to improve palliative and end-of-life care. The Committee stressed that attention be directed to issues dealing with support to family caregivers, access to home care and pharmacare, training and education, research, and surveillance.

In December 2000, community-based pressure to address palliative and end-of-life care issues came to the forefront with the formation of the Quality End-of-Life Care Coalition (QELCC). The Coalition developed the Blueprint for Action, which identified five key priority areas for intervention:

- availability and access to services;
- professional education;
- research and data collection including surveillance;
- family and caregiver support; and
- public education and awareness.

The QELCC currently represents 30 national voluntary and professional organizations interested in palliative and end-of-life issues.

In March 2001, Prime Minister Jean Chrétien appointed Senator Sharon Carstairs as Minister with Special Responsibility for Palliative Care and advisor in that capacity, to the federal Minister of Health. In June of that year, Health Canada established the Secretariat on Palliative and End-of-Life care to act as a focal point and facilitator of collaborative action in palliative and end-of-life care.

In March 2002, the Secretariat hosted the National Action Planning Workshop on End-of-Life Care in Winnipeg, Manitoba where over 150 national organizations, provincial,territorial and regional practitioners, researchers, educators, and government officials participated in the development of a five-year action plan for advancements in palliative and end-of-life care. Participants made recommendations for action in seven priority areas including: availability and access to services; education for health care providers; research; surveillance; support for family caregivers and significant others; ethical, cultural and spiritual realms; and, public education and awareness. The identification of time lines, roles and responsibilities, and possible evaluation mechanisms were also included in the action plan. A copy of the National Action Planning Workshop on End-of-Life Care's final report is available on the Health Canada website at *www.hcsc.gc.ca/english/palliative.html*

CANADIAN STRATEGY ON PALLIATIVE AND END-OF-LIFE CARE

Following a discussion of possible structural models for implementation of the action plan, a June 2002 face-to-face meeting of the National Action Planning Workshop's Steering Committee, additional consultation with the community, and a letter of intent sent to major organizations, the Secretariat established five working groups. The working groups were organized to address issues in the areas of best practices and quality care, education for formal caregivers, public information and awareness, research, and surveillance. It was determined that the crosscutting themes of access to services and programs, and ethical, spiritual and cultural considerations would be taken into account and applied by each of the working groups as they developed and implemented their respective initiatives.

Working group members were selected from across Canada based on their geographic location, expertise and involvement in palliative and end-of-life care. Members represent a variety of interests and community stakeholders including: researchers; educators; care providers; volunteers; corporations; various professions and professional associations; and, regional, provincial and national organizations. Working group initiatives are facilitated and supported by the Secretariat.

A Coordinating Committee comprised of the co-chairs from each working group, a representative each from the Aboriginal community, the Quality End-of-Life Care Coalition and Health Canada, was established to ensure overall coordination of the implementation of palliative and end-of-life care initiatives. It also serves to identify overlapping areas of interest across the five working groups for opportunities to create synergy and to reduce duplication.

The working groups and Coordinating Committee work together to support the improvement of palliative and end-of-life care for Canadians and provide a forum through which Health Canada can facilitate collaboration, by identifying priorities and activities members can undertake in their specific areas.

The overall responsibilities of the working groups include the:

- provision of a forum for innovative forward thinking and assistance in developing and implementing the Canadian Strategy;
- participation in the ongoing development of a Canadian palliative and end-of-life strategy, including suggesting appropriate future activities and direction for the stakeholder community, federal government and others;
- identification of issues of specific relevance, defining the relationships required for implementation, and propose approaches to address these issues;
- collaboration with key national organizations to address palliative and end-of-life issues, and the recommendation of specific strategies;
- identification of priorities for each working group and integrating them into an overall workplan; and,
- commission of knowledge development work as required to address gaps in knowledge to inform policy recommendations.

The members are also responsible for championing palliative and end-of-life care as a national priority. An alphabetical listing of Coordinating Committee and working groups' members can be found at the end of this report (Appendix I).

ACCOMPLISHMENTS

The expertise, dedication and innumerable hours of volunteered time and effort of the members of each working group, their special project or task groups, and the Coordinating Committee have been instrumental to the accomplishments realised by the community. The Committee is pleased to report on the working groups' accomplishments from their establishment in December 2002 to the end of March 2004. It is important to bear in mind that much of the work marks only the beginning of the foundational work required to significantly influence equitable access to quality palliative and end-of-life care for all Canadians. When available, final reports or results from various working groups' initiatives can be accessed through the Health Canada website or by contacting the Secretariat.

Best Practices and Quality Care Working Group

The Best Practices and Quality Care Working Group (BPQCWG) was mandated to promote, facilitate and coordinate activities related to best practice and quality care by focussing on the application of the Canadian Hospice Palliative Care's (CHPCA) A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, often referred to as simply, the Norms of Practice. (A copy of the Norms of Practice is available at *www.chpca.net*)

The BPQCWG has been working in partnership with the Canadian Council on Health Care Service Accreditation (CCHSA) to influence hospice palliative care accreditation across Canada. This includes national hospice palliative care accreditation standards, an accreditation program for free-standing hospice and volunteer programs, and a set of national indicators to assess care and inform future action. This collaborative initiative will lead to the implementation of standards for hospice palliative care in all existing accreditation programs by 2007. Standards help ensure that the accredited service provider meets the criteria required for best practices to ensure quality care delivery.

The process toward establishing national paediatric standards has begun using existing standards and practice employed by the Canuck Children's Place in Vancouver and the Toronto Hospital for Sick Children. The results of this work will help to respond to the needs of children and their families when accessing palliative and end-of-life care services for children across Canada.

The Working Group is pleased to highlight that a project on best practices and quality in the volunteer sector involved in hospice palliative care, received international recognition at the Nordic Association of Palliative Care as ground breaking work. A Model for Volunteer Best Practice in Canadian Hospice Palliative Care is the development of a framework to guide a wide range of activities that support the

desired outcome of having volunteers available to provide care and support services to patients and family as full members of the palliative care interdisciplinary team. The project involves a consensus process. The Nordic Association represents Iceland, Norway, Sweden, Denmark and Finland.

Education for Formal Caregivers Working Group

The Education for Formal Caregivers Working Group (EFCWG) was mandated to identify educational needs for formal caregivers delivering palliative care. This includes reviewing and influencing curricula for palliative and end-of-life care in undergraduate, post-graduate and continuing professional development. Formal caregivers are members of an organization and therefore accountable to defined norms of conduct and practice.

Initiatives to help ensure optimal education and training for formal caregivers in palliative and end-of-life care were the focus of this Working Group's efforts. Following an overview of palliative care education of undergraduate and post-graduate physician, nursing, social work, pharmacy and chaplaincy training programs, the EFCWG established core discipline competencies for formal caregivers (undergraduate and post-graduate physicians, nursing, social work, pharmacy and chaplaincy), and achieved national consensus via a Professional Competencies Consensus Survey. The result of this work is available through Health Canada's Secretariat on Palliative and End-of-Life Care.

The Working Group was successful in it's funding application for interprofessional development of physicians, securing $1.25 million over four years to develop palliative and end-of-life care training for physicians. The project strives to bring palliative and end-of-life care medical education to all undergraduate medical students and clinical postgraduate trainees at Canada's seventeen medical schools so that they will graduate with core competencies in this area. This collaborative initiative of professional organizations, led by the Canadian Hospice Palliative Care Association (CHPCA) and the Association of Canadian Medical Colleges (ACMC), will also help shape the development of parallel programs in nursing, social work, pharmacy and chaplaincy. For further information contact CHPCA in Ottawa at (613) 241-5663 or 1-800-668-2785.

Public Information and Awareness Working Group

The Public Information and Awareness Working Group (PIAWG) was mandated to cover issues related to information sources, tools and dissemination relative to the full range of hospice, palliative and end-of-life care for the Canadian population with attention given to ethical and spiritual considerations, community-based and cultural sensitivities, and language.

The Working Group completed two phases of a three-phase project to develop a framework or communication plan for a national public awareness raising initiative on palliative and end-of-life care. The plan capitalizes on current awareness raising communication activities. It is intended that the plan be used by the stakeholder community and other interested parties to help increase Canadians' understanding of palliative care and where to access information services or programs when needed.

The PIAWG and a representative of the Research Working Group worked in partnership with CHPCA and the GlaxoSmithKline Foundation, to establish benchmarks of Canadians' awareness, understanding and use of palliative care and to capture Canadians' understanding and views on advance care planning. This was accomplished using Ipsos-Reid's Canadian Omnibus poll conducted from December 9th to 11th, 2003. The results of the survey will help facilitate future assessments and evaluation of the effect of the Working Group's and other Canadian Strategy initiatives over a five to eight year period. For more information about the poll contact CHPCA in Ottawa at (613) 241-3663 or 1-800-668-2785.

As part of its work to promote dialogue and discussions on dying and planning for end-of-life, the PIAWG through the Best Practices and Quality Care Working Group, ensured that the accreditation standards under development include advance care planning.

The PIAWG was directed by the Coordinating Committee to address the informational needs of informal caregivers (family, friends and loved ones) in actual or anticipated palliative and end-of-life situations. Informational needs were identified and defined from both service providers' and informal caregivers' perspectives. The results of this work and other related work will inform future action to ensure that primary caregivers, their patients, and families and loved ones have timely access to appropriate information. To assist informal caregivers with some of their immediate information needs, the Canadian Hospice Palliative Care Association (CHPCA) developed an inventory of information tools for informal caregivers who are currently in, or who are anticipating they may be involved in, palliative care. The inventory is available on the Association's website *www.chpca.net*

Research Working Group

The Research Working Group (RWG) works collaboratively with the Canadian Institutes of Health Research's (CIHR) National Working Group on Palliative Care Research. The National Working Group is co-chaired by a CIHR representative and a Health Canada representative. It assists with infrastructure development and strategic planning for palliative and end-of-life care research, advocates for research funding specific to palliative and end-of-life care, and helps to ensure that the focus is broader than cancer.

The RWG completed a business plan to support the creation of a palliative care research infrastructure in Canada, including a network of researchers. Such a network would provide support, interaction, and application of research findings to improve practices, education, and policy. The first step in establishing this network was to build an interactive database for researchers. Health Canada supported its development at the Canadian Virtual Hospice (CVH), an interactive network for people dealing with lifethreatening illness and loss *www.virtualhospice.ca*

An overview of the uptake of health research for palliative care was completed. The key findings from interviews with thirteen experts and identified needs are summarized in a report that will be available on Health Canada's website in the summer of 2005.

The RWG organizes and facilitates protocol development meetings for established and junior researchers in palliative and end-of-life care to increase rese ch capacity and to advance the theory and methodology of palliative care research. This will lead to the provision of an evidence base for practice and decision-making in policy. The first protocol development meeting was held in Toronto, October 2003 and it is anticipated that others will be held in the next year. The Terms of Reference for the meetings are available through the Secretariat on Palliative and End-of-Life Care.

Surveillance Working Group

The Surveillance Working Group (SWG) was mandated to address issues related to the development of systems for national surveillance of hospice, palliative and end-of-life care. This includes determining which data should be collected, the method of collecting and analysing, and the uses it would serve. The purpose is to provide the evidence that supports the need for and access to quality palliative and end-of-life care in all corners of the country.

The SWG completed a feasibility study and a pilot project to develop a core data set and method for data collection for palliative care surveillance. A core set of data must be collected for all palliative patients in order to describe and assess the characteristics and appropriateness of palliative admissions or referral. It is also used to provide b eline and comparative data for audit and surveillance purposes at all levels of governance. A study to determine all of the sources of palliative and end-of-life care data is planned.

Further more, in the absence of standards or norms of practice for assessing the quality of palliative care service delivery, a set of core national indicators is under development at a program level for assurance in palliative care delivery. The indicators will identify the key components for quality assurance and will serve as the basis of program evaluation and comparisons.

Summary of Working Group Accomplishments

In summary, the working groups' foundational work is contributing to an overall increase in Canadian's knowledge of hospice, palliative and end-of-life care and is leading to the development of tools, best practices, and education for the public, volunteers, and professional caregivers. Information gathering, knowledge transfer, and data collection and comparison will provide the evidence base necessary to influence health and social care policy to improve programs and service delivery for citizens in need of hospice, palliative and end-of-life care. In the true spirit of collaboration, the working groups have also been very successful in forging relationships and in leveraging additional in-kind and funding support to advance their work.

We have only just begun. Much work remains to successfully effect change in the availability of and accessibility of quality palliative and end-of-life care programs and services for all Canadians.

CHALLENGES

Achieving progress for the Coordinating Committee and working groups has not been without its challenges. There were a number of factors that influenced our ways of working and the level of success in meeting the goals and objectives of the working groups' workplans: a lack of adequate and sustained funding to support working group and other community-oriented initiatives; changes in Secretariat staff and working group membership; changes in government, in particular the end of the portfolio of Minister with Special Responsibility for Palliative Care; organizational constraints; and, the unique situation of working in large and diverse groups.

There were a number of other considerations that have influenced and will continue to influence the overall impact and success of working groups' initiatives. Some of these include the:

- on-going commitment, volunteered hours of expertise, and leadership of the Coordinating Committee, working groups' members and their networks, to advance current and emerging issues;
- requirement for strengthened federal commitment and leadership, and the need for sustained funding support to enable strategic development and implementation of the national strategy;
- difficulty of addressing issues and undertaking initiatives to advance the

palliative care approach and practice in a society that is focussed on cure and prevention, and that is technologically advanced, multi-jurisdictional, multi-cultural, and multilinguistic;
- task of reaching consensus at a national level which requires optimum representation from a broad cross-section of sectors, experts and others, who tend to have diverse objectives and needs;
- differences between community and government processes and procedures;
- timely and appropriate engagement of provinces and territories in the development of the Strategy; and,
- identification of best ways to forge partnerships and to instigate effective, collaborative efforts between the community, federal, and provincial and territorial components of the national strategy.

Some of these challenges reflect the environment in which we continue our efforts, and others will be addressed in our future work. Separate from our work with the Secretariat on Palliative and End-of-Life Care and our work on Canadian Strategy activities, concentrated effort is underway by the palliative and end-of-life care community to secure sustained financial assistance from the Government of Canada for the ongoing development and implementation of the Strategy.

MOVING FORWARD

March 2004 was identified as the time for the Coordinating Committee's review of, and reflection on, the progress and impact of working group activities on the development and implementation of the community component of the Strategy.

The accomplishments briefly described in this report illustrate the in-roads we have made and the immediate and potential impact leading to change in the health and social care systems that directly affect the lives of Canadians. Our work acknowledges the importance of linkages across the sectors, it appreciates the sometimes intricate relationships and processes needed to successfully carry-out objectives, and respects the interdependencies of each activity and its results.

As demonstrated in the results of the March 2002 Action Planning Workshop and the activities of the working groups, there is considerable consensus among health sector communities and others involved in hospice, palliative and end-of-life care, on the elements and actions to be included in a national strategy for palliative and end-of-life care. The Committee recognizes that it is necessary to seek that same level of consensus from the social sector, other federal government departments,

and the provincial and territorial governments to effectively reach the goal of equitable access to quality palliative and end-of-life care.

We support the articulation of a national strategy that is flexible and overarching in scope; a strategy that reflects a "whole system" partnership among the people of Canada and their communities, care providers, health and social sector organizations, and the federal, provincial and territorial governments. Progress would be achieved as each of the participants with a role and responsibility for improving outcomes in hospice, palliative and end-of-life care create their individual and collective action plans using the guiding principles of the overall strategy.

It holds true that the subject and issue-focussed initiatives of the Coordinating Committee and the working groups, are critical to informing the development and implementation of the community component of the national strategy. They are pivotal to informing and influencing the federal, and provincial and territorial activities of a national strategy, ultimately in addressing the hospice, palliative and end-of-life care needs of Canadians. It is paramount that the Government of Canada continue to provide human resources and commit to sustained financial support to make certain that what has been accomplished is not lost, what has begun continues, and what has yet to be developed is enabled.

The Coordinating Committee and working groups' members look forward to continuing this journey; exploring opportunities for collaborative partnerships, defining the best ways to maximize efforts, and optimizing results for Canadians in need of hospice, palliative and end-of-life care.

APPENDIX I

Canadian Strategy on Palliative and End-of-Life Care

MEMBERS OF COORDINATING COMMITTEE AND WORKING GROUPS

The following list includes all community members who have served on one of the five Canadian Strategy working groups and the Coordinating Committee from December 2002 to March 2004. In alphabetical order they are:

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